NHANES Genetics Program

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August 24, 2015
Encourage research at the intersection of genetics and public health using NHANES
NHANES DNA Repository and Genetic Data Program

- Unique DNA research collection – nationally representative
- Combine population-level genetic data & health risk factor and outcome data
  - dietary, environmental, health care information
Program inception

- Began in 1991
- Two parts
  - DNA Specimen Repository
  - Genetic Data Repository
DNA Specimen Repository

- Maintains DNA specimens for future genetic studies
- Requires approved proposal to gain access
- Resulting genetic data combined with other NHANES data
DNA collection

  - Ages 12 years and older

  - Ages 20 years and older
Specimen collection and processing

- Consent obtained to collect blood for future studies
- Blood collected at NHANES mobile exam center
- DNA isolated from blood and stored
  - CDC National Center for Environmental Health (NCEH) Molecular Biology Laboratory
### Number of participant DNA specimens

<table>
<thead>
<tr>
<th>NHANES survey cycle and eligible sample n</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>NHANES III</td>
<td>7159</td>
</tr>
<tr>
<td>1999-2002</td>
<td>7839</td>
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<tr>
<td>2007-2008</td>
<td>4615</td>
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<tr>
<td>2009-2010</td>
<td>3898</td>
</tr>
<tr>
<td>2011-2012</td>
<td>~3800</td>
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</tbody>
</table>
Researcher’s access

Prior to 2012

• Researchers submitted proposal
• Approvals
  • NHANES Genetic Technical Panel
  • NCHS Human Subjects Officer
  • NCHS Confidentiality Officer
  • NCHS Ethics Review Board
• Agreement signed, specimens received
Resulting genetic data

- NHANES quality control review
- Genetic variants restricted access
- Genetic variants available for analysis in NCHS Research Data Center
Program Revaluation after 2012

- Concerns about returning results to participants

- Program paused to reevaluate – no new proposals reviewed

- February, 2014 workshop
  - Sponsored by NCHS and National Academy of Science Committee on National Statistics
  - Expert geneticists and bioethicists participated
Program Revaluation after 2012

• Workshop Outcome – *existing DNA specimens*, concerns did *not* support need to report results

• March 2015 – approved re-opening DNA Specimen Repository
  - NCHS Board of Scientific Counselors
  - NCHS Ethics Review Board
  - January 2016 – plan to accept new proposals
Publications using NHANES Genetic Data

• >60 publications in peer-reviewed journals
  • Human Genetics
  • Annals of Human Genetics
  • Genetic Epidemiology
  • Epidemiology
  • American Journal of Epidemiology
Thank you

More information

www.cdc.gov/nchs/nhanes/biospecimens/biospecimens.htm